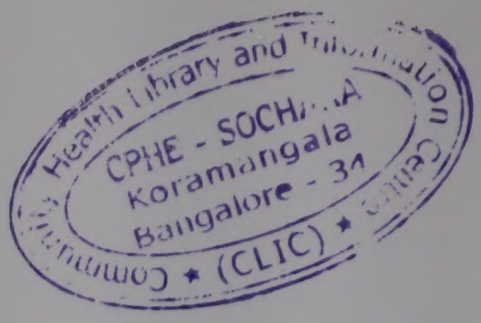
HIV/AIDS Care at the Institutional, Community and Home Level

World Health Organization
Regional Office for South-East Asia
New Delhi, India



SEA/AIDS/65

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Report of a WHO Regional Workshop

Bangkok, 29 March – 2 April 1993

World Health Organization
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1. BACKGROUND

Since the beginning of the HIV/AIDS pandemic, prevention and care programmes in most countries have been planned and implemented with a primary focus on prevention of the spread of infection. However, programmes providing care for those infected with HIV and AIDS are yet to be adequately developed. In addition to the physical symptoms of the disease, persons with HIV/AIDS are affected emotionally and, together with their families, are often ostracized and suffer from social discrimination and rejection. Medical care alone is not enough; tolerance and compassion for individuals, families and communities affected by the virus are required as well. A greater degree of community involvement is also necessary to provide family members with hope and support. In a majority of South-East Asian countries, health care providers and programme managers need assistance and support to face the varying and increasing needs created by the AIDS pandemic and to do so with limited resources. HIV/AIDS care, integrated into the whole spectrum of health care services needs, to be developed using the existing infrastructure at all levels.

Considering the increasing numbers of HIV/AIDS cases in South-East Asia and recognizing the expected burden on health structures in the Region, a Regional Workshop on HIV/AIDS Continuum of Care at the Institutional, Community and Home Level was organized in Bangkok from 29 March to 2 April 1993.

The objectives of the workshop were to:

(a) review existing experiences of care for HIV/AIDS within families, communities and health service institutes, including attitudes of care providers at all levels;

(b) discuss strategies for HIV/AIDS care in South-East Asia and identify current and future needs across the continuum of care, that is, at the institutional, community and home levels, with special emphasis on community participation and the role of the family;

(c) propose approaches and strategies for strengthening HIV/AIDS care and counselling along the continuum of care, and

(d) identify ways of strengthening collaboration between governments and NGOs with regard to HIV/AIDS care.

The workshop was attended by a total of 29 participants from 9 countries: Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand. They were mainly senior health officials, representatives of national AIDS committees and representatives of NGOs (including professional associations). In addition, there were representatives from national, regional and international organizations, including provincial communicable disease control officers from Thailand, Thai NGOs, and the United Nations Development Programme (UNDP) as well as WHO staff (see Annex 1 for full list).

The workshop was inaugurated by Dr Paichit Pawabutr, Permanent Secretary, Ministry of Public Health, Thailand, who reminded the participants that, because health and community support services for persons infected with HIV/AIDS are still new to most people in the Region, the workshop was a good opportunity to collect and disseminate information and share useful experiences. Alliances with NGOs and community programmes were emphasized, as well as the moral and professional responsibilities of health professionals to care for people with HIV/AIDS. The need for living rationally and compassionately infected with AIDS was stressed.

The opening session was also addressed by the WHO Representative to Thailand, on behalf of the WHO Regional Director for South-East Asia. The Regional Director stressed the magnitude of the expected increase in the numbers of HIV/AIDS cases and their serious consequences for the national health care systems and for socioeconomic development. To face these upcoming challenges, urgent attention must be given to the development of comprehensive care services for HIV/AIDS-affected persons. These challenges necessitate strong commitments from governments at the policy level and the combined strengths of health care professionals, NGOs, communities and families at the operational level. A message from WHO/GPA underlined the fact that misconceptions and ignorance about HIV/AIDS lead to fear and stigmatization. As a result, these irrational fears among health care workers (doctors, nurses and others) lead to neglect of medical attention for people with HIV/AIDS. Thus there are now two immediate related challenges: the need for all health professionals to overcome fear and to provide care, counselling and compassion to HIV/AIDS-affected people.

2. WORKSHOP PROCEDURES

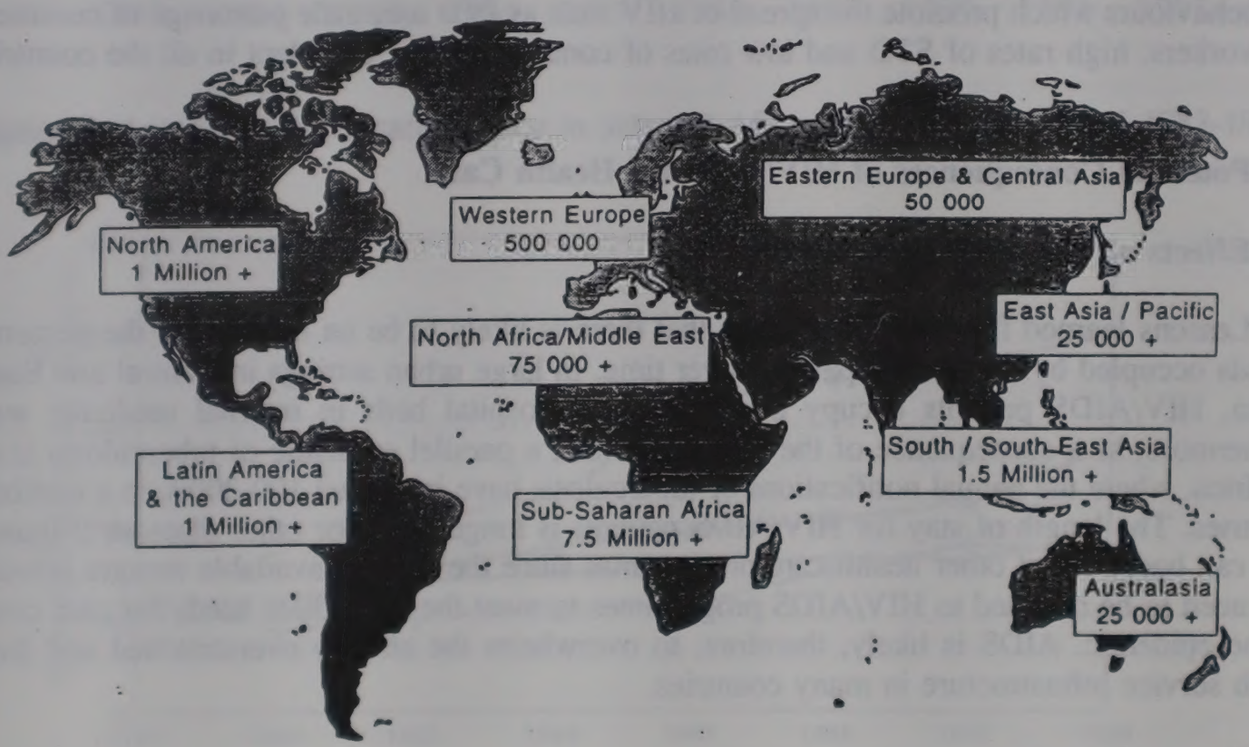
To achieve the objectives of the workshop, background papers and presentations were introduced and discussed in plenary sessions. (see Annex 2 for workshop programme and Annex 3 for list of background material). Experiences in HIV/AIDS care from selected African countries were highlighted. Field visits were organized in Bangkok for observation of different aspects of the continuum of care at home, community, institutional and tertiary referral levels. With this background, participants prepared broad outlines for action plans to strengthen the continuum of care in their own countries. Recommendations for follow-up action were also formulated and discussed.

3. HIV/AIDS PANDEMIC AND CONSEQUENCES

3.1 Global and Regional Situation

WHO estimates of global HIV infection in late 1992 suggest that approximately 13 million persons are infected with the HIV virus, worldwide (Figure 1). The largest number of infections are in Sub-Saharan Africa (7.5 million), followed by South and South-East Asia (1.5 million). WHO further predicts that by the year 2000, the cumulative number of adults and children infected with HIV will rise to 30-40 million, and the number of AIDS cases will go up to 12-18 million.

Figure 1. Estimated Distribution of Cumulative HIV Infections in Adults, by Continent or Region: Late 1992



In the South-East Asia Region, out of 1.5 million HIV-infected individuals, India, Thailand and Myanmar account for the largest number. As of February 1993, a total of 1,331 AIDS cases have been reported to the South-East Asia Regional office of WHO, Thailand (946 cases), India (307 cases) and Sri Lanka (22 cases) accounting for the largest number of AIDS cases (Figure 2). No AIDS cases have so far been reported from Maldives, Bhutan, Mongolia or DPR Korea. Due to various reasons it is assumed that the number of cases reported is considerably less than the actual number of cases. WHO estimates that by the end of the decade, the cumulative number of patients with AIDS in South-East Asia will be close to 2 million.

There is grave concern that despite the late entry of HIV/AIDS into the South-East Asia Region, the epidemic may be spreading here at a pace reminiscent of Sub-Saharan Africa in the early 1980s. In countries such as Thailand, India and Myanmar, there has been a dramatic increase in HIV prevalence rates among intravenous drug users, commercial sex workers and STD patients, and there is evidence to indicate that the virus is spreading rapidly from these groups to the general population.

Although many other countries in the Region report a low level of HIV at this time, there is every reason to expect a similar scenario being repeated in all the countries. This is because the risk behaviours which promote the spread of HIV such as IVD use, male patronage of commercial sex workers, high rates of STD and low rates of condom use are prevalent in all the countries.

3.2 Potential Consequences of HIV/AIDS for Health Care

(1) Effects on the health care system

Lessons learned from Africa indicate that there is likely to be an increase in the percentage of beds occupied by HIV/AIDS patients over time. In large urban settings in Central and Eastern Africa, HIV/AIDS patients occupy 60-70% of the hospital beds in internal medicine wards. Furthermore, as a consequence of the HIV pandemic, a parallel epidemic of tuberculosis is seen in Africa, where the annual notifications of tuberculosis have increased 100-200% in a number of countries. The length of stay for HIV/AIDS patients is longer than for other diseases (Figure 3). This can badly affect other health care programmes since the already available meagre resources may need to be diverted to HIV/AIDS programmes to meet the immediate needs for care created by the epidemic. AIDS is likely, therefore, to overwhelm the already overstretched and fragile health service infrastructure in many countries.

(2) Economic costs

The financial implications of HIV/AIDS for health care systems in South-East Asia and its magnitude cannot be underestimated. For instance, a study carried out in Thailand in 1990 suggests that the personal, direct and in-patient care cost per patient per year reaches 107% of the per capita gross national product (GNP). Indirect care costs are estimated in a 1991 study as being approximately 54 to 83% of the per capita GNP. Direct costs to institutions occur in the areas of prevention, care and research. With regard to care, institutional costs include those of beds, staff, supplies and drugs.

Figure 2. Reported AIDS Cases in SEAR Countries

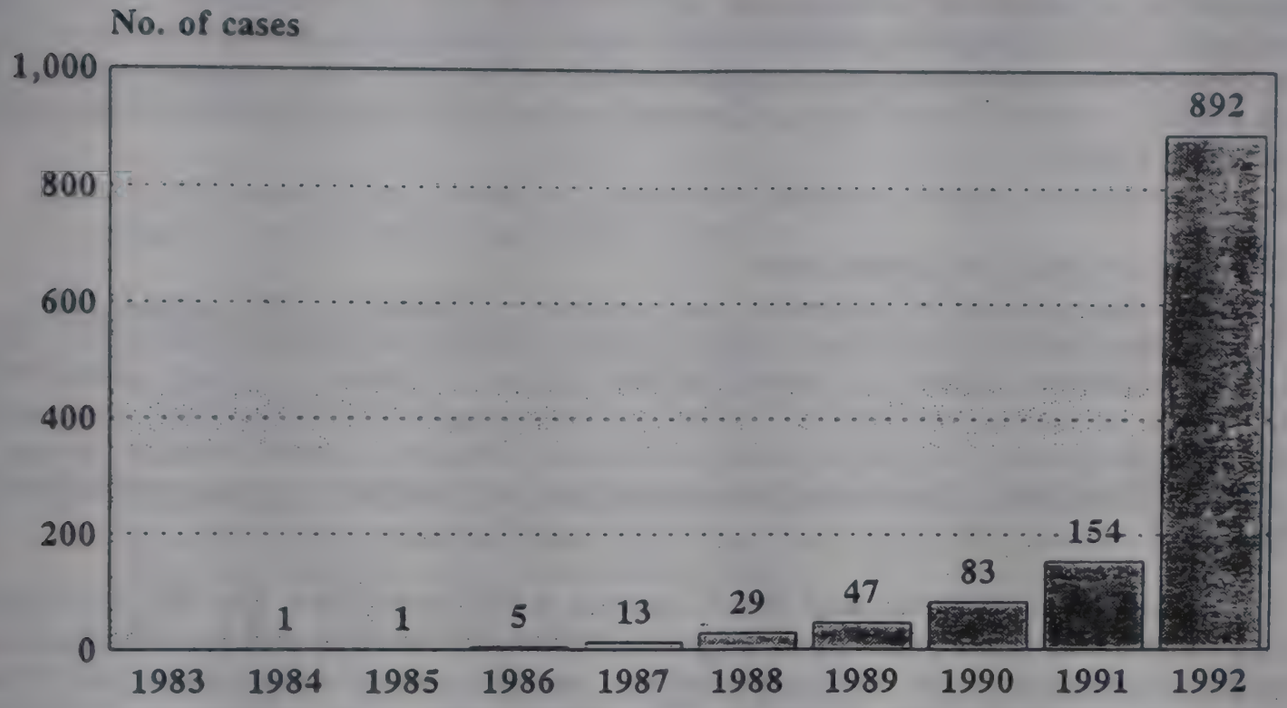
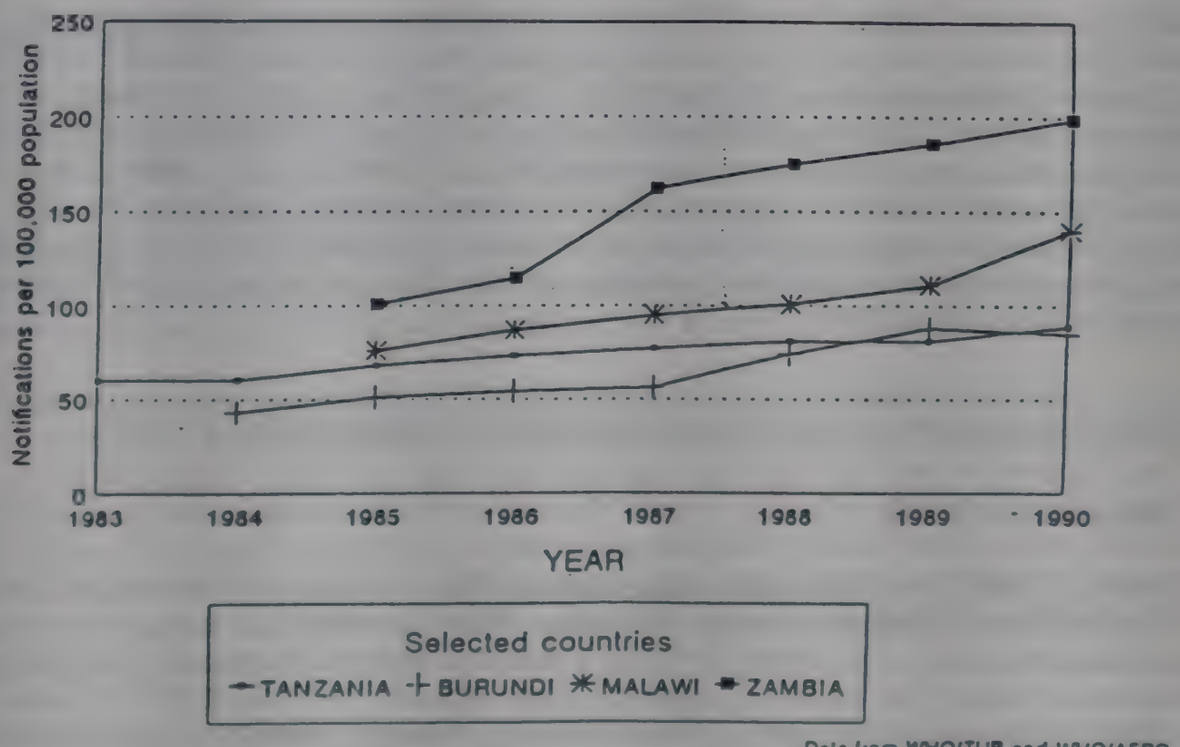


Figure 3. Annual TB Notification Rates in Selected African Countries (all cases) 1983-1990



Data from WHO/TUB and WHO/AFRO

In addition to medical and health care costs, thousands of lives in the most productive age groups will be lost depriving families and communities of the productive years of life. Child survival rates can be expected to decrease in the Region. These factors can lead to indirect costs in the form of absenteeism and decreased productivity, which will have a major impact on the already fragile economies in the Region. Community costs for the care of orphan children add to the economic burden.

(3) Effects on health care professionals

Fear, stigma and discrimination are early responses of health care professionals to HIV/AIDS. Fear is a spontaneous response to something that is fatal. The desire to isolate patients with HIV/AIDS is a consequence of this fear. Further, ignorance about HIV/AIDS and lack of capability in providing appropriate care lead to neglect of patients. Conversely, commitment to the care of HIV/AIDS-affected persons can lead to considerable stress and possible burn-out among health care professionals.

This issue is an important one in many countries at the present time. The lack of adequate training for health care professionals on the issues related to HIV/AIDS care and the absence of universal precautions in most health care settings contribute to the reluctance of health care professionals to treat individuals affected by HIV. Presently, only a few health care professionals in each country are handling HIV/AIDS cases and there is a tendency for other health care professionals to refer cases to these few individuals, thereby putting them at risk for burn-out, and, at the same time, pressing on families for extensive travelling.

Despite the severe burden that AIDS places on health care systems, it also presents a unique opportunity for these systems to improve and strengthen themselves. Integration of HIV/AIDS care into all levels of health care along the continuum of care will not only help minimize the financial implications of HIV/AIDS for the health care system, but can also strengthen general health care. For example, skills in palliative care or counselling can benefit many patients with chronic conditions. Universal precautions prevent all blood-borne infections and home care can address follow-up of malnutrition or tuberculosis as well. Dealing with patients and their families provides ample opportunities for more effective prevention efforts. There can be no care without prevention and no prevention without care.

4 THE CONCEPT OF COMPREHENSIVE HIV/AIDS CARE

4.1 Components of Care

HIV/AIDS is different from many other health problems: infection is life-long and eventually fatal. Transmission is related to sexual behaviour, which is usually a domain of privacy and secrecy. Initial reactions of society to HIV/AIDS have thus been characterized by fear, stigma and discrimination, leading to social rejection of those affected by HIV/AIDS. In some cases, inappropriate public health measures have followed, driving vulnerable groups underground. Innovative approaches for broad and humane care of those affected by HIV/AIDS are thus urgently needed.

As a first step to develop new approaches for HIV/AIDS care, it is crucial to identify the needs of those infected and their families. Rapid appraisals of the medical, psychosocial and welfare needs of HIV/AIDS-affected persons should be conducted with the active participation of the patients, families and communities. Based on these needs, a comprehensive HIV/AIDS care programme can be developed. This should cover four areas:

(a) Clinical management, including appropriate diagnosis using flowcharts, rational treatment and discharge planning for follow-up.

(b) Nursing care, including maintenance and promotion of hygiene and nutrition, enforcement of infection control practices, provision of palliative and terminal care, education of family and community members in providing care, preventive education and promotion of condom use.

(c) Counselling, including helping individuals make informed decisions on HIV testing, stress and anxiety reduction, planning for the future, promoting positive living and networking, and promoting behavioural change.

(d) Home and community-based care, including training of family members, neighbours and community members as care providers, provision of supervision/guidance by community-based workers and social workers, managing common symptoms, providing palliative care and moral support, providing support for families to maintain hygiene, nutrition, and providing linkages to social welfare systems.

4.2 Continuum, Linkages and Referral

The provision of comprehensive services for HIV/AIDS-infected persons and their families relies on the provision of care across a continuum. This continuum of care extends across various levels of the health care system. It links facilities such as national hospitals, district hospitals, health centres and village health posts, as well as families in their homes and supportive community networks. In other words, HIV/AIDS care is not only integrated into all levels of the health care system, but also includes whole communities and families in the spectrum of care, and thus ensures the provision of care throughout the life span of AIDS patients.

Community-based care, which provides psychological, social, medical and nursing support to HIV-infected persons and their families, is seen by many countries as the only realistic approach to cope with the crisis. Care for chronic conditions is given by families and members of society in the home and at the community level through hospice and other shelter settings, while health settings support community-based care by providing diagnosis, clinical management, and treatment of acute conditions. Thus, referral networks between communities and health settings are key elements of the continuum of care which includes homes, communities, and health settings at various levels.

Community-based care can further be defined as the interaction of support mechanisms of communities and governmental and nongovernmental organizations to meet the physical, emotional, social and spiritual needs of persons who are sick. Community-based care should build on or make use of the strengths of communities and families and should take into account social and cultural norms and traditions. Community health workers, community development groups, religious groups,

traditional practitioners, volunteers and social workers are involved in raising community awareness, initiating preventive activities and coordinating social support.

Home-based care refers to the provision of services by family members, neighbours or trained community members within the home, to meet the physical, emotional, social and spiritual needs of people who are sick. These services can be supervised by existing support mechanisms in the community.

4.3 Integration with Primary Health Care

HIV/AIDS care must be integrated into all the existing programmes of primary health care. In many countries, during the initial phase of the HIV/AIDS epidemic, there was a tendency to establish separate AIDS care programmes and special AIDS wards. While these may apparently seem to be good solutions in the earlier phase where models of care were shown for teaching purposes, they have the disadvantage of further alienating general wards from taking the responsibility for the care of HIV/AIDS patients and following universal precautions. In addition, the establishment of such separate or exclusive programmes lead to problems with regard to confidentiality, discrimination towards individuals affected by HIV from other patients and health care workers, as well as increased stress and burn-out for those health care workers who are singularly responsible for the care of persons affected by HIV/AIDS.

Integrating HIV/AIDS care programmes into all existing primary health care activities can help strengthen both programmes. For example, integrating HIV/AIDS and tuberculosis programmes can go a long way towards enhancing both the programmes. It is estimated that one-third of the 1.5 million HIV-infected individuals in South-East Asia are co-infected with tuberculosis. Tuberculosis comes early in HIV infection. Health workers dealing with AIDS or tuberculosis thus need to know about prevention and care of both. Community-based and home care programmes can thus deal with a variety of health issues at the home level such as malnutrition, AIDS and tuberculosis.

The integration of HIV/AIDS prevention and care programmes across the continuum of care, including communities and families, has the following advantages: (i) General health services at primary health centres and community-based health centres can be strengthened; (ii) Prevention efforts are enhanced as it becomes easier to involve families and communities, develop networks among persons with AIDS/HIV (PWA), and normalize AIDS in the community; (iii) There will be increased confidence in the health care system, (iv) PWAs and their families feel more involved and thereby improve their quality of life, and (v) the sustainability and effectiveness of the programmes are enhanced through the integrated approach.

4.4 Positive Experiences from Africa

(1) TASO experience

The AIDS Support Organization (TASO) is a voluntary non-profit organization founded in Kampala, Uganda, in 1987 by a group of people, many of whom were themselves infected with HIV. TASO has evolved from developing a hospital-based model of HIV/AIDS care and counselling, to providing medical home care and setting up community-based programmes. The primary goal of TASO is to empower people to live positively with AIDS. Their programmes

include AIDS education and prevention to help those not infected to protect themselves from exposure to the virus, as well as care components for those already infected. Their primary strategy has been to include HIV/AIDs persons as well as those who may not know their serostatus as care providers for people with AIDS. Community involvement has been a key strategy in TASO's success. Most of the demand for community involvement came from the communities themselves, so that community mobilization was relatively easy. However, it was emphasized that organizations in other countries do not necessarily have to wait for communities to come forward before developing community-based interventions. Since a lot more information is available today as compared to what was available for TASO when it began, and since there are models and experiences from different countries, these can be used to educate communities not to react with rejection and stigmatization and to point out the consequences of such a community response.

Another strategy that is encouraged is to mobilize NGOs working in areas other than HIV/AIDS to integrate HIV/AIDS prevention and care programmes into their existing work. Most importantly, TASO focuses on the needs as well as the responsibilities of individuals, families and communities affected by AIDS. The primary responsibility of people with HIV is not to spread it to others. They need to make arrangements for their dependants, as well as seek ways to support themselves and their families, both financially and emotionally. Communities are responsible for fighting discrimination and stigmatization, for spreading positive messages about care and living positively, for strengthening links with NGOs and health care facilities, and for strengthening community solidarity.

(2) Chikankata Hospital, Zambia

In 1986, when the first AIDS cases were identified, Chikankata Hospital in Zambia considered isolating AIDS patients in an old leprosy building. However, it was realized that the space was not large enough to cope with the numbers, and the approach was not built on family strengths and that there was no need to isolate AIDS patients. The initial tendencies to blame AIDS victims and to consider AIDS a shameful disease turned towards constructive approaches, including hospital discharge planning and home follow-up for AIDS patients. By 1992 a special care ward for all terminally ill patients had been created. On this ward family members are trained to give care at home by transferring knowledge and skills to them in a setting where support is available. Home visits by a hospital team gave an opportunity to strengthen links with community leaders and, through a process of awareness raising, community leaders took an active role in changing social norms which could put people at risk for HIV infection.

(3) Kenyatta National Hospital, Kenya

HIV/AIDS education and counselling is provided at various levels in the hospital, according to the level of need. Health education and support is provided by peer educator volunteers from the local AIDS support society. Individual or small group counselling is provided on the wards by doctors and nurses who have been trained in HIV/AIDS counselling. For ongoing counselling and psychosocial support, a counselling centre has been created, staffed by counsellors with extensive training. The most difficult and complex cases involving mental disturbances are referred to clinical psychologists and psychiatrists for specialist care. This hierarchy is meant to provide the relevant services to those in need using the available human resources.

(4) Monze District, Zambia

The model used by the district hospital attempts to decentralize care for AIDS patients by developing a referral network, using the rural health centres within the hospital catchment area. All HIV/AIDS patients are discharged through the counselling unit in the hospital. Guidelines are prepared for the staff in the rural health centre. The rural health centres along with the community health workers and traditional practitioners are in the front line to support the family care-givers providing AIDS care in the home. This type of integration of community-based AIDS care into the existing district health service based on primary health care principles has the potential to avoid setting up an AIDS programme as a vertical service.

4.5 Experiences of Care in Thailand

Although a great deal remains to be accomplished in Thailand as in other countries in the South-East Asia region, a good beginning has been made. Thailand has identified as its priority areas, clinical management, nursing care, counselling and home care. With regard to clinical management, the main focus seems to be on improving diagnostic methods for opportunistic infections as well as developing guidelines for discharge planning and follow-up.

- Programmes in Chulalongkorn Hospital and Bamrasnaradura Infectious Disease Hospital provided excellent opportunities for country participants who had never seen persons affected by HIV/AIDS in their own countries to observe AIDS care. These hospitals emphasize the need for universal precautions to develop greater confidence among health care workers, the need for medical, nursing and other personnel to be involved in counselling, better coordination among the different care institutions, and the need for integration of STD and tuberculosis prevention programmes into HIV/AIDS care programmes and vice versa.

- NGOs providing counselling services, such as Access and the Hotline Center Foundation, are examples of the various kinds of counselling activities that can be developed for different target groups. Telephone counselling, individual counselling for persons infected with HIV/AIDS, as well as counselling for their partners and families at counselling centres located in hospitals, radio talk shows to educate as well as support persons affected by HIV/AIDS, support groups for people affected by HIV/AIDS as well as training programmes for counsellors and peer educators are some of the ongoing activities that these NGOs are involved in.

- PWA groups, such as the Wednesday Friends Club and Concrete House, are gradually emerging in Thailand primarily to provide support to those who are infected, to keep in touch with the latest developments on the medical front, to mobilize resources to fight discrimination and stigmatization, and to promote proper understanding and positive attitudes towards persons affected by HIV.

- Community-based initiatives are also in evidence. The Duang Prateep Foundation, which is essentially a slum-based community development organization, has prevention and education programmes targeted at IV drug users and female sex workers in their community as well as for the community as a whole and uses volunteers from the community to spread their messages.

- NGOs, such as the Association for the Promotion of the Status of Women and the International Network of Engaged Buddhists (INEB), are actively seeking to expand their areas of work and provide services for individuals affected by HIV. The former has recently begun to provide shelter for women who are HIV positive, while INEB is working towards encouraging temples in Thailand to set up hospices for people infected with AIDS and provide spiritual support to individuals and families affected by HIV.

5. CHALLENGES AND OPPORTUNITIES

5.1 HIV/AIDS Counselling

It should be noted that counselling is an integral part of comprehensive care for HIV/AIDS. While most countries focus on clinical management at the initial stages of the disease, counselling tends to be neglected. Health care professionals are not oriented to counselling in their training programmes. Therefore, political will to strengthen counselling at all levels, as well as to introduce it into the curricula of all health professionals, is urgently required.

During the early stages of the pandemic, the issue of HIV testing and counselling was often the focus of much debate. While it is now generally agreed that testing must be accompanied by counselling, there is still uncertainty about the implementation of vast counselling training in different testing contexts, particularly at blood banks, and when there is widespread testing for research purposes. The rationale of mandatory testing, particularly for individuals in the so-called high-risk groups, is often said to be related to health; in fact, neither individual nor public health benefits result from such testing. General guidelines regarding HIV testing and counselling include:

(a) Whenever HIV testing is recommended by medical personnel in order to make a clinical diagnosis, when individuals voluntarily seek to be tested for HIV, or when individuals have given informed consent for participating in research that includes HIV testing, testing must always be accompanied by pre-and post-HIV test counselling.

(b) Blood must be screened at the blood transfusion centres to ensure HIV-free blood supply. As long as no attempt is made to trace blood donors who test positive, there is no need to routinely inform blood donors about their HIV status. However, if pre- and post-HIV test counselling services are available, it would go a long way towards

encouraging donors to seek out information with regard to HIV/AIDS as well as their own serostatus.

(c) Only unlinked, anonymous testing may be conducted for HIV sentinel surveillance where blood is collected in order to determine epidemiological trends over time. All personal identifiers on records and test tubes will be removed. Neither clients nor personnel involved in such testing can thus have access to any data. Nobody can link the result to a client tested. Under such circumstances, counselling is not necessary.

Ethical issues surrounding HIV testing, such as informed consent, confidentiality and the responsibilities of the health care professionals towards HIV-positive persons, as well as towards HIV-negative persons, are also important considerations. Examples from some countries in the Region show gaps in counselling services. There is an urgent need to develop and adapt counselling training manuals. Counselling in medical settings is relatively unusual in many countries. Medical professionals need to be oriented about the importance of counselling, particularly in the context of HIV/AIDS. Counselling training is also needed for selected health and social care professionals at all levels of the health care system, as most countries in this region may not be able to afford the creation of a specialized cadre of counsellors. However, it should be pointed out that while this was highly desirable, health care professionals may already be over-burdened and thus might not appreciate new responsibilities on top of all their existing ones. Prioritization of duties (new job descriptions) and expressed willingness to be trained as a counsellor are prerequisites for the establishment of such a service.

5.2 Coping with Fear and Stigma

Community-based care is possible only in the context of tolerance, support, and solidarity. However, experiences in countries outside the SEA Region suggest that community tolerance usually follows waves of denial, fear, stigma, and discrimination, and after AIDS awareness and education is widespread.

This is not to suggest that countries recently affected by HIV/AIDS must necessarily go through the same steps. It is merely a realistic view of what usually happens. This should motivate SEAR countries to identify strategies for dealing with these potential barriers. It should also be recognized that community-based approaches cannot be imposed on people unless they have been prepared through education and awareness programmes. However, community tolerance and family acceptance cannot be encouraged unless and until health care professionals themselves show acceptance and tolerance towards HIV/AIDS-affected people.

As a first step towards establishing care for HIV/AIDS, health care professionals must learn to identify and deal with their own fears and misconceptions about HIV/AIDS. Educating health care professionals about universal precautions as well as ensuring that these universal precautions are implemented in all health care settings, can go a long way towards decreasing the fears and insecurities of health care professionals.

To sensitize health care workers to the psychosocial needs of individuals and families affected by HIV/AIDS, they should be told about the personal experiences of HIV/AIDS-affected individuals and family members. These presentations can emphasize the need for humane care and support for individuals, families, and communities living with HIV/AIDS. National AIDS programmes are encouraged to begin mobilizing support for people affected by HIV/AIDS in their respective countries, and to discourage initiatives that would lead to isolation, stigmatization and neglect. The negative attitudes of health care professionals towards HIV/AIDS and their consequent reluctance to care for patients with HIV/AIDS are areas of primary concern in many countries. There is an urgent need for strategies that would lead to positive attitudes towards HIV/AIDS among health care professionals.

Attitudes cannot be changed easily and repeated exposure to change attempts might be needed. The need for change should be clearly perceived and change appeals should not create too much fear among recipients. Considerable patience is required to bring about an attitudinal change. It is not very helpful to criticize or attack persons with negative attitudes; such strategies have the paradoxical effect of hardening attitudes. It is important to understand the cultural beliefs and values of individuals, institutions, and communities so as to contextualize existing attitudes and to find acceptable frames for new ones. Provision of factual information, sharing of experiences and exposure to positive role models are useful strategies for bringing about attitudinal change.

5.3 Issues Related to Women and Children

As the epidemic progresses in this region, it is expected that women will bear the brunt of the physical and emotional consequences of HIV/AIDS. The traditional roles that women assume, their lack of education, and lack of assertiveness in relationships with men are just a few of the factors that make it difficult for them to protect themselves from exposure to the virus.

Also, since the burden of caring for the sick traditionally falls upon women in their role as mothers, wives and nurses, special attention to the needs of women as care givers is required.

As in Africa, the increasing numbers of AIDS cases expected in the South-East Asia Region will also result in large numbers of "AIDS orphans", children who have lost both parents to the disease. Children will also have to assume the role of care-givers as their parents begin to fall sick and face the risk of being emotionally overburdened at an early age.

These are all issues that require specific attention and community-based programmes; in particular, those working with women and children should be motivated and strengthened to respond to these anticipated social crises. Large-scale institutionalization of women and children should be completely avoided and communities should be motivated to care for them and support them.

5.4 Priorities for South-East Asia

It is now clear that with increase in HIV/AIDS in the future, countries of South-East Asia need to establish HIV/AIDS care as an integral part of AIDS prevention and care programmes.

While prevention still remains a high priority, care of HIV/AIDS patients and their families also needs adequate attention. Other issues that need urgent attention are the following:

- Training of health care workers in clinical care and universal precautions is needed, along with adequate supplies to ensure the practice of these activities.
- Routine or mandatory HIV testing should be discouraged in any health care setting. Instead, universal precautions must be implemented.
- Pre and post-test counselling should accompany any HIV testing. Informed consent prior to testing is essential.
- Voluntary testing and counselling services should be accessible to the community and should be established in keeping with the available resources.
- Steps should be taken to remove barriers to the establishment of home-based care, such as stigma and loss of confidentiality.
- Adequate financial support should be provided for establishing programmes for HIV/AIDS continuum of care.
- Guidelines and other evaluation methods should be developed to evaluate care programmes and to assess the sustainability of the programmes.

Each country prepared a plan to fit its own priorities, and broad recommendations regarding HIV/AIDS care were agreed upon during the meeting.

6. WORKSHOP RECOMMENDATIONS

In the face of a growing pandemic in South-East Asia, comprehensive HIV/AIDS care programmes, including clinical management, nursing care, counselling and social support require strengthening in most countries. Involvement of community groups, NGOs and religious groups is a crucial step to be considered. Integration of HIV/AIDS care into other health care programmes with emphasis on home-based care was recognized as an important step towards a better quality of life for the HIV/AIDS-affected and their families. The links between prevention and care provide opportunities to contribute to health education and to the dissemination of messages aimed at reducing further spread of HIV in the community. The need for compassion, acceptance and tolerance at all levels should also be highlighted.

The following recommendations for governments, international agencies, and non-governmental organizations were generated during the workshop and were adopted by the participants.

6.1. Action by Governments

(1) Governments need to formulate a policy for the establishment of care for persons affected by HIV/AIDS, as a priority component of AIDS prevention and control efforts. Commitment needs to be reflected in the allocation of adequate resources, and by assigning a national focal point and a working committee with the responsibility of planning, implementing, monitoring and evaluating HIV/AIDS care.

(2) HIV-infected people should be able to receive care in any health setting according to the nature of their illness. Therefore all areas of care (i.e., medical, surgical, obstetrical, paediatric, etc.) should be prepared to provide care to HIV/AIDS-affected persons. Drugs required for the management of associated opportunistic infections should be incorporated in the essential drug supply system.

(3) Existing primary health care systems based on community participation need to be strengthened with the integration of comprehensive care for HIV/AIDS-infected persons. Referral services and access to higher levels of care should be strengthened. Training of community and family personnel to cope should be undertaken.

(4) Clear guidelines and policies on the management and discharge of patients infected with HIV/AIDS should be established. Manuals and training material should be culture-specific and the experience of NGOs needs to be incorporated. Procedures for universal precautions should be implemented in all health care facilities for the safety of the patients and the care providers, creating greater confidence in both groups.

(5) Basic and in-service training for all categories of HIV/AIDS care providers should promote positive attitudes among them in order to reduce fear and stigma.

(6) Governments should adopt national policies on HIV testing, including confidentiality. There is no medical or public health rationale for screening or routine testing of specific risk groups or patient groups. This practice should be abolished. However, all HIV testing related to individual diagnosis of HIV/AIDS undertaken in health care settings and/or in voluntary testing centres should be accompanied by pre and post-test counselling. All other HIV testing procedures (i.e., for surveillance), should be unlinked and anonymous.

(7) Governments should adopt strategies to develop counselling services, since improvements in counselling of persons infected with HIV/AIDS and their families can go far towards reducing the spread of the infection and decreasing the stress among those affected by HIV/AIDS.

(8) Governments, in coordination with the private sector, NGOs and communities, should ensure that HIV/AIDS-affected individuals and families have access to legal services with respect to employment, human rights, property and rights of women and children.

(9) The role of communities in strengthening their own capability for coping with HIV/AIDS through effective awareness raising and development of activities at the peripheral level needs to be developed and supported through governments and nongovernmental organizations.

(10) Communities should be encouraged to promote or restore positive traditions of acceptance and tolerance, and discourage those that might lead to isolation or discrimination. Integration of care and social welfare of women and of AIDS orphans into all community-based activities needs urgent attention. Spiritual support for the affected individuals and their families needs to be considered according to the local culture. The importance of indigenous systems of care should be recognized and they should be integrated into community-based care programmes.

6.2 Action by International Agencies

(1) WHO should provide technical support to strengthen HIV/AIDS care programmes in Member Countries. The development and exchange of training materials on comprehensive care should also be promoted.

(2) Operational research with qualitative and quantitative components to improve care activities should be supported. Priority areas for such research should be identified.

(3) Monitoring and evaluation methods based on clear indicators should be included in future workshops and training programmes on care.

(4) WHO/SEARO should support the documentation and dissemination of case studies of successful projects in the management and control of AIDS across the continuum of care, carried out in the countries.

6.3 Action by Nongovernmental Organizations

(1) In view of the limited resources of the governments in the Region, nongovernmental organizations should play a major role in implementing and supporting HIV/AIDS care activities across the continuum.

(2) Nongovernmental organizations should develop a mechanism for better collaboration with national AIDS programmes and between themselves in order to maximize the use of available resources for the care of people affected by HIV/AIDS.

As a follow-up to this workshop and in order to achieve the longer-term objective of strengthening HIV/AIDS care, proposals drawn up by the participants in the workshop need to be finalized in their respective countries and submitted to national authorities for incorporation into existing plans and for seeking assistance from sources such as WHO and other agencies.

Annex 1

LIST OF PARTICIPANTS

Bangladesh

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Annex 2

PROGRAMME

Sunday, 28 March 1993

1400 hrs Early Registration for Workshop Participants at "Krungthep 2" Meeting Room

Monday, 29 March 1993

0830 hrs Open Registration for all Participants

0900 **Inaugural Session**

- Opening Address by Dr Paichit Pawabutr, Permanent Secretary, Ministry of Public Health, Thailand
- Address by Dr U Ko Ko, Regional Director for South-East Asia, World Health Organizaton

1000 **Introduction of Participants and Secretariat and Review of Workshop Objectives**

Dr J.P. Narain and Dr Eric van Praag

1030 **Consequences of HIV/AIDS**

- "Consequences of HIV/AIDS in South-East Asia" – Dr J.P. Narain
- "Consequences of HIV/AIDS to the Health Care System" – Dr Eric van Praag
- "Consequences of HIV/AIDS to the Individual" – Mr Suraphongse Wattana

1330 **Coping with Fear and Stigma**

- Small Group Discussions and Exercises – Dr Sandra Anderson
- "Countering Discrimination in the Community – Ms Noerine Kaleeba
- "Developing Positive Attitudes Among Health Care Workers" – Dr Chitra Subrahmanian

1530 **HIV/AIDS Continuum of Care**

- "An Overview of HIV/AIDS Care" - Dr Eric van Praag
- "Examples of HIV/AIDS Care from Selected Countries" - Dr Sandra Anderson
- Discussion

Tuesday, 30 March 1993

0830 hrs **Components of HIV/AIDS Care**

- Panel Discussion: Dr Dounia Bitar (Chairperson)
- "Clinical Management" – Dr Somsit Transuphaswadikul
- "Nursing Care" – Daw Khin San Kyi
- "Social Welfare" – Dr Kusum Sehgal
- "Counselling and Support" – Mr Jon Ungphakorn

1030 **HIV/AIDS Care and Counselling: The TASO Case Study**

Part I: "Living Positively with AIDS – The TASO Story"
Part II: "Counselling: The TASO Experience"

Discussion and Country Experiences in HIV/AIDS Care and Counselling – Ms Noerine Kaleeba

1330 **Issues Concerning HIV/AIDS Counselling and Testing**

- Panel Discussion – Dr Eric van Praag (Chairperson)
- "HIV/AIDS Counselling and Testing: The India Experience" – Ms Chitra Subrahmanian
- "HIV/AIDS Counselling and Testing: The Thai Experience" – Dr Chanuanthong Tanasugarn
- "Ethical Issues in Counselling and Testing: – Dr Dounia Bitar

1600 **Issues Concerning Women and Children**

- Khunying Kanitha Wichiencharoen, President, Association for the Promotion of the Status of Women, Thailand
- Ms Noerine Kaleeba
- Audio/Visual Presentation: "These Are Our Children"

1700 Orientation to Field Visits

Wednesday, 31 March 1993

Field site visits

Group One:

0930 hrs
1230

- Duang Prateep Foundation
- Chulalongkorn University Hospital
- Thai Red Cross Programme on AIDS
- Wednesday Friends' Club

Group Two:

0930 Hotline Center Foundation
1100 Bamrasnaradura Infectious Disease Hospital
1400 Concrete House

Thursday, 1 April 1993

0830 hrs Reports and Discussions on Field Visits

1030 Introduction to Working Groups

- To identify priority areas across the continuum of care – institutional, community and home – which need strengthening to cope with the HIV/AIDS epidemic
- To identify constraints, resources, and gaps in these priority HIV/AIDS care areas
- To suggest possible approaches to bridge the gaps in HIV/AIDS care

1330 Working Groups (continued)

1530 Discussion of Draft Recommendations

Friday, 2 April 1993

0830 hrs Presentation and Synthesis of Working Group Objectives

- Priority Areas
- Constraints, Resources and Gaps
- Approaches

1030 Adoption of Draft Recommendations

1130 Official Closing of Workshop

Annex 3

LIST OF MATERIAL DISTRIBUTED

Background Information

1. AIDS in South-East Asia: No Time for Complacency, WHO Regional Office for South-East Asia, New Delhi, 1992
2. AIDS and Asia: A Development Crisis, A UNDP Report, 1992
3. Janovasky K. Project Formulation and Proposal Writing (WHO/EDUC/87.187)
4. WHO/GPA Resource List for HIV/AIDS Care and Counselling, 1993
5. AIDS in South-East Asia, 7 November 1992

Clinical Management

6. Guidelines for the Clinical Management of HIV Infection in Adults (WHO/GPA/IDS/HCS/91.6)
7. Draft Guidelines for the Clinical Management of HIV Infection in Children
8. Draft Adapting Guidelines for the Clinical Management of HIV Infection: A Facilitator Guide
9. Draft AIDS Drug Estimator
10. HIV-Associated tuberculosis in developing countries: Epidemiology and Strategies for Prevention; and clinical features, diagnosis and treatment

Counselling

11. Guidelines for Counselling about HIV Infection and Disease, AIDS Series 8 and overhead insert

Community-Based Care

12. Review of Six Home-based Care Programmes in Uganda and Zambia (GPA/IDS/HCS/91.3)
13. Report of the World Health Organization/Commonwealth Secretariat Regional Workshop on HIV/AIDS Community Based Care and Control, 6-11 October 1991, Entebbe, Uganda
14. Living with AIDS in the Community (WHO/UNICEF, Geneva, 1992)

Maternal Child Health

15. AIDS Prevention: What Maternal and Child Health Service Providers Need to Know, Regional Health paper, SEARO No. 23, New Delhi, 1992

Nursing

16. HIV/AIDS Reference Library for Nurses, WPRO, 1991 and 1992